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Original Research

Equity of uptake of a diabetic retinopathy screening programme in a geographically and socio-economically diverse population

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SUMMARY

Objectives: At the time of undertaking the audit, the uptake of diabetic retinopathy screening in Derbyshire was 73%, below the national standard of 80%. To assess equity of access to diabetic retinopathy screening in a geographically and ethnically diverse population and determine predictors for poor uptake that will inform service improvements.
Study design: Mixed methods health equity audit.
Methods: Postal questionnaires were issued to 1000 people invited for diabetic retinopathy screening in May 2010 and telephone interviews were conducted with subsample of 32 people who had not made a screening appointment. Routine data from the screening programme was used to identify characteristics of people who did not respond to screening invitation. The adjusted odds ratios (OR) and 95% confidence intervals (95% CI) using multivariate methods were calculated in this study.
Results: The response rate to the postal questionnaire was 43%. Of these, 28% of respondents did not recall discussing the importance of diabetic retinopathy screening with their primary care team and 11% of people did not understand the term 'diabetic retinopathy'. Non-uptake of screening was associated with deprivation (OR 1.19, 95% CI 1.10–1.29 for those living in the most deprived areas compared to the least deprived) and young people were over three times more likely not to participate than older people (OR 3.13, 95% CI 2.70–3.64 for men under 40 compared to men over 80 and OR 3.03, 95% CI 1.54–5.98 for people with type 1 diabetes under 40 compared to those over 80).
Conclusions: Ensuring that primary care and other health care and third sector organisations convey the importance of diabetic retinopathy screening with patients and improving patients' understanding of the screening programme may improve uptake. Interventions to increase uptake should be targeted to younger people, especially those with type 1 diabetes and people living in more deprived areas.

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Introduction

Globally more than 366 million adults are living with diabetes and that this will rise to over 522 million by 2030.[1] People with diabetes are at risk of developing macrovascular complications such as coronary heart disease and microvascular complications such as diabetic retinopathy (DR). Diabetic retinopathy causes changes in the blood vessels of the retina that can lead to blindness and is one of the leading causes of blindness in working-age people in England and Wales.[2] The prevalence of DR is strongly associated with the duration of diabetes and it is estimated that nearly all patients with type 1 diabetes and approximately 60% of patients with type 2 diabetes will have some degree of DR 15–20 years after diagnosis.[3,4] As the disease progresses it impacts upon the quality of life of patients and makes the disease and any co-morbid illnesses difficult to manage.[5–7] Screening tests for diabetic retinopathy can detect changes in the retina before symptoms commence and early laser treatment can then be given at an appropriate stage to slow the progression of the disease and to reduce the risk of moderate and severe visual loss by up to 50%.[8,9]

Screening for DR has been shown to be cost[10] and clinically[11] effective at the population level and is now offered (free of charge) to all eligible people with diabetes in the UK.[12] In England it is expected that local programmes will screen at least 80% of their eligible population annually as set out in national quality standards. However a 2011 report from the UK National Screening Committee on the performance of DR screening in England in 2009/10 showed that uptake of DR screening was below this.[13] Whilst ensuring high uptake continues to present a challenge, currently little is known about the predictors for DR screening uptake.

At the time of the audit the uptake of DR screening in Derbyshire was 73%. However the programme in Derbyshire includes residents of Derby City and Derbyshire County. Both areas are extremely diverse in terms of the geography that they cover and population demographics; Derbyshire County covers a population of 760,000 with just under 5% black and minority ethnic residents, whilst Derby City covers a population of 244,000 with nearly 12% black and minority ethnic residents. Its geography includes rural National Park areas, a dense inner city conurbation and one district in the most deprived quintile of the UK. At the time of the analysis, screening was delivered in 12 fixed sites: two sites in the city and ten sites in the county.

A mixed-methods approach was used to assess the equity of screening uptake in Derbyshire and to identify potential barriers to service access. To do this a postal survey of 1000 patients with diabetes, supplemented with short telephone interviews with people who did not attend their screening appointment was conducted. In addition, the routinely-collected data from the Derbyshire Diabetic Retinopathy Screening Programme was used to identify the characteristics of people who were less likely to take up their offer of DR screen.

Methods

Study design, setting and participants

1000 postal questionnaires were sent to a stratified sample of patients who had been invited for screening between 1st and 31st May 2010. The stratifications were district of residence, gender and age and the size of each stratum was proportionate to the population who did not respond to the screen in the previous year with the exception of type of diabetes; all patients with a record of type 1 diabetes ($n = 148$) were invited and the remainder were either people with type 2 diabetes ($n = 809$) or people with unknown type of diabetes ($n = 43$).

Demographic information was collected to assess how representative the responses were. In the questionnaire, patients were asked about their most recent contact with the screening programme. This included questions about the ease of booking an appointment, experiences with staff and the screening clinic, the quality of the information (verbal and written) and views about potential changes to the local service.

From this sample of 1000 patients, the authors attempted to conduct telephone interviews with 50 patients selected at random who had been invited to make a screening appointment but had not done so within six months following invitation. In total, 32 interviews were conducted and were structured based on the questions in the postal questionnaire.

In addition to the survey and telephone interviews, prospectively collected routine data from the Derbyshire DR screening database were used to assess access to the screening programme. The population consisted of a closed cohort of people with diabetes aged over 12 years that had been invited for DR screening between January 2009 and July 2010. Where people had been invited twice in the time period, only the time of the first invitation were looked at. The characteristics of the people who did (responders) and who did not (non-responders) make an appointment for screening within six months of invitation were described. If individuals made an appointment for screening more than six months after invitation they were classed as non-responders because the target time for screening had elapsed.[14] The characteristics of people who were assessed were selected because they had been identified in previous studies as potential independent risk factors for poor screening uptake[15–17] and were routinely available in the database. They were: age at the time of invitation, gender, type of diabetes and level of deprivation. Patients were grouped into the following age categories: under 40, 40–49, 50–59, 60–69, 70–79 and 80 and over. The Index of Multiple Deprivation (IMD 2007) score assigned to the GP practice that the patient was registered with, split into quintiles was used to measure deprivation.

Statistical analysis of the routine data

Characteristics of responders and non-responders were described using frequencies and percentages. Logistic regression was used to estimate univariable and multivariable

odds ratios (OR) with 95% confidence intervals (CI) for non-response to invite associated with potential predictive variables.

Patients who had been invited for screening even though they were no longer eligible or had become ineligible between invite and appointment were removed from the data prior to analysis. This was to minimise ascertainment biases since these people would have been classed as non-responders even though screening was either not possible or inappropriate. These exclusions included people who were: already under the care of an ophthalmologist, deceased, had since been discharged from the screening programme, had moved out of area, had their diagnosis of diabetes changed to no longer diabetic, had lost postal contact, had no perception of light in both eyes, or had refused the current or any future offer of screening.

Multivariate models were built and significance assessed with likelihood ratio tests (LRT).[18] All covariates described above were included in the initial model and age and sex were retained as *a priori* confounders. Potential interactions between covariates were identified *a priori* based on theoretical plausibility. Interaction terms were added to the model, significance assessed using a LRT and those with a *P*-value of <0.05 were retained in the model. The final model was tested for multicollinearity using the covariate correlation matrix and by calculating the variance inflation factor. Missing data were included as a separate category in the analysis.

All analyses were conducted using Stata version SE11.

Results

Barriers to screening uptake

The overall response rate to the postal questionnaire was 43% (435 returned) and varied by age, sex, type of diabetes and district of residence (Table 1). Of those who responded, 93.7% were white British, with only 27 questionnaires returned from other ethnic groups and most had previously had an eye screening appointment (98%).

When asked if the GP or practice nurse had spoken to the patient about diabetic eye screening over a quarter of respondents (28%) said 'no' or 'not sure'. This result was similar for people with type 1 and 2 diabetes. When asked, 88% of people felt that the written information was easy to understand but 36% of people did not remember seeing the information leaflet which is issued with every invitation. When asked if the written information clearly explained the term 'diabetic retinopathy' 11% of people did not know what it meant, were still unsure or had never heard of it. Patients were asked if they had been offered a diabetic eye screen by their optician and 36% said yes, even though the nationally specified screening programme is not delivered by optometrists in Derbyshire.

In Derbyshire, patients are issued with an open invitation to make a screening appointment that suits them. When asked if they would prefer a fixed appointment invitation, i.e. an invitation with a prespecified date and time, the response

Table 1 – Characteristics of people who responded to the questionnaire.

Age	Issued	Returned (%)	Issued	Returned (%)
	Male		Female	
Under 40	38	7 (18)	36	7 (19)
40–49	29	8 (28)	80	33 (41)
50–59	247	100 (40)	99	43 (43)
60–69	123	49 (40)	104	58 (56)
70–79	93	54 (58)	97	47 (48)
80+	17	14 (82)	37	14 (38)

Location	Issued	Returned (%)
City	278	107 (38)
County	722	331 (46)

Ethnicity	Returned (%)	Derby City	Derbyshire County
White British	403 (93.72)		
White Irish	4 (0.93)	85.8	96.9
Any other white background	2 (0.47)		
Any other mixed background	1 (0.23)	2	0.5
Indian	8 (1.86)		
Pakistani	7 (1.63)	8.9	1.36
Bangladeshi	1 (0.23)		
Any other Asian background	1 (0.23)	1.1	0.6
Caribbean	3 (0.7)	2.2	0.58

Type of diabetes	Issued	Returned (%)
Type 1	148	25 (17)
Type 2	809	602 (74)
Unknown	43	4 (9)

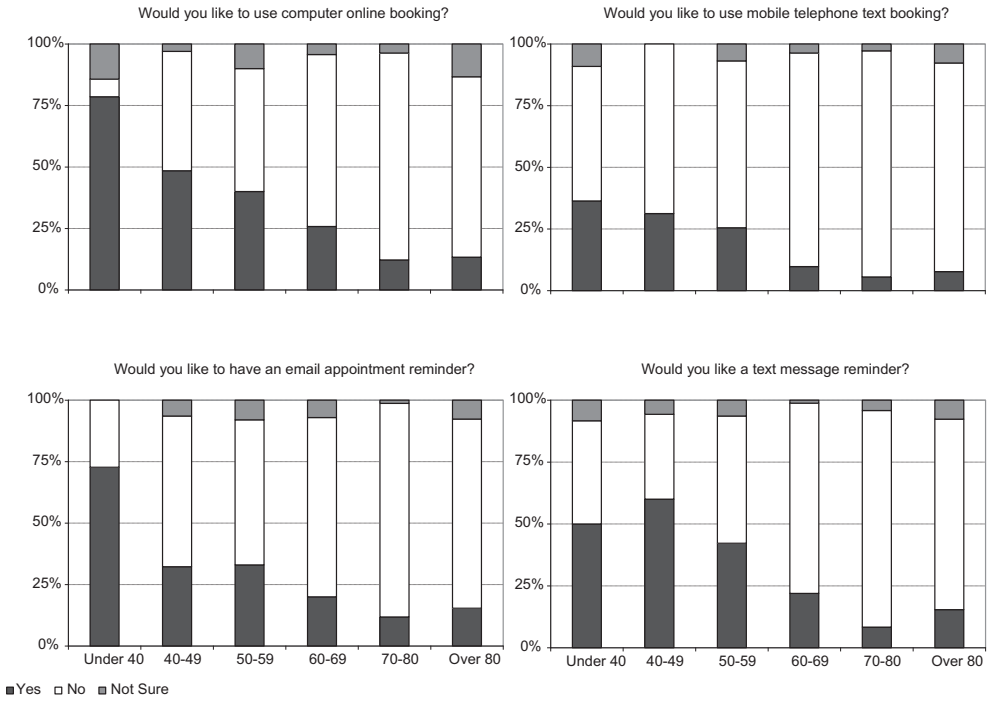

Fig. 1 – Booking preferences of patients eligible for DR screening.

Table 2 – Characteristics of responders and non-responders and unadjusted odds ratios for non-response to screening invitation.

Characteristics	Non-responders frequency (%)	Responders frequency (%)	Unadjusted odds ratio (95% CI)	*P*-value
Sex				
Male	6759 (54.9)	19,449 (55.9)	1.00	
Female	5540 (45.1)	15,363 (44.1)	1.04 (0.99–1.08)	0.080
Patient age				
80+	1936 (15.7)	5680 (16.3)	1.00	
70–79	2188 (17.8)	10,138 (29.1)	0.63 (0.59–0.68)	
60–69	2597 (21.1)	9936 (28.5)	0.77 (0.72–0.82)	
50–59	2470 (20.1)	5394 (15.5)	1.34 (1.25–1.44)	
40–49	1803 (14.7)	2413 (6.9)	2.19 (2.02–2.37)	
Under 40	1305 (10.6)	1251 (3.6)	3.06 (2.79–3.36)	Test for trend <0.001
Type of diabetes				
Type 2	7588 (61.7)	30,939 (88.9)	1.00	
Type 1	895 (7.3)	1642 (4.7)	2.22 (2.04–2.42)	
Unknown	3816 (31.0)	2231 (6.4)	6.97 (6.58–7.39)	<0.001
Area of residence				
Rural (County)	8405 (68.4)	24,871 (71.4)	1.00	
Urban (City)	3878 (31.5)	9932 (28.5)	1.15 (1.104–1.21)	
Unknown	16 (0.1)	9 (0.1)	5.26 (2.32–11.90)	<0.001
Deprivation (IMD score assigned to GP practice)				
(1) Least deprived	1766 (14.4)	5250 (15.1)	1.00	
(2)	2140 (17.4)	6124 (17.6)	1.04 (0.96–1.12)	
(3)	2558 (20.8)	7713 (22.2)	0.98 (0.92–1.06)	
(4)	2574 (20.9)	7941 (22.8)	0.96 (0.90–1.03)	
(5) Most deprived	2926 (23.8)	6895 (19.8)	1.26 (1.18–1.35)	
Not known	335 (2.7)	889 (2.5)	1.12 (0.98–1.28)	Test for trend 0.14

varied by age; 30% of people under 40 said they would prefer a fixed appointment compared to over 70% of people over 80 said they would prefer this. Younger people also liked the idea of online booking, mobile phone text booking and appointment reminders by email and text as shown in Fig. 1. Older people liked these options less.

Qualitative semi-structured interviews

A total of 32 patients were interviewed by telephone and were selected because they had not made an appointment as a result of their most recent invitation. No comparative demographic data were collected for participants in these qualitative interviews. The postal questionnaire was used as a guide for the interviews and several themes emerged. Reflecting the responses in the questionnaire, many people were not familiar with the term 'diabetic retinopathy', although they did appreciate that diabetes can damage the eyes. People often felt that they needed more information about diabetic retinopathy and the importance of regular screening. Rather than making a deliberate decision not to be screened, patients said that they often simply forgot to make their screening appointments or had other health concerns that were seen as a higher priority. Interviewees felt that people would be less inclined to go for screening again if previous screening results had repeatedly been clear or if the interviewee didn't remember receiving the results from their GP, as they would assume everything was fine and that it was not worth the effort of attending the screening again. People who did not speak English were not interviewed as part of this work.

Characteristics of people who did and did not respond to screening invitation

Between 1 January 2009 and 31 July 2010 47,111 eligible people (26,208 (55.6%) men) were invited to make a DR screening appointment. The mean age (standard deviation) of people who were invited to be screened was 64.0 (14.1) years for men and 66.6 (15.2) years for women. The characteristics of people who did and did not respond to screening invitation are shown in Table 2. Of those invited, 12,299 (26.1%) did not make an appointment (6759 (54.9%) were men). The mean age for those who did not respond to screening invite was 59.1 (15.8) for men and 63.4 (17.9) for women. Of people eligible to be screened over 50% of those under 40 years did not respond to this offer compared to 20–30% in the older age groups (Fig. 2). This was supported by the univariate analysis which showed that people aged under 40 were over three times more likely to be non-responders than those aged over 80 (OR 3.06 (95% CI 2.79–3.36)).

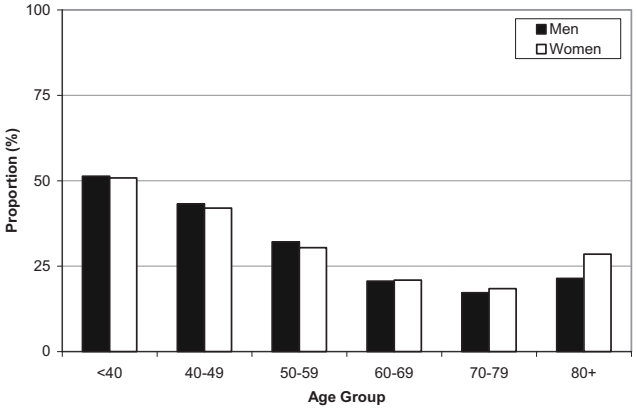

Fig. 2 – Proportion of men and women in each age group that did not respond to screening invite.

A higher proportion of people had type 1 diabetes in the non-responder group compared to those who did take up the offer of screen (7.3% vs 4.7% in the responder group) and a higher proportion of people in the non-responder group had the type of diabetes missing from their record (31% vs 6.41% in the responder group). In Derbyshire, the type of diabetes that a patient has is entered in the screening database at the first screening appointment attended. People who lived in the City were 15% more likely to be non-responders compared to people in the County (OR 1.15, 1.104–1.21) as were people who lived in the most deprived areas (OR 1.23, 1.18–1.35 for the most deprived compared to the least).

Multivariate models (Table 3) showed similar results to the univariate analysis although area of residence (city or county) was not identified as a predictor of non-attendance and was not therefore included in the model. There was a significant interaction between gender and age of patient and also age of patient and type of diabetes. Overall the under 40 age group were 2–3 times more likely to be non-responders than the over 80 age group but this effect was stronger in younger men than younger women (OR 3.13, 95% CI 2.70–3.63 for men under 40 vs OR 2.23, 95% CI 1.92–2.59 for women under 40) and was stronger for people with type 1 diabetes than people with type 2 or unknown type of diabetes (OR 3.03, 95% CI 1.54–5.98 for people with type 1 diabetes under 40 vs over 80). Interestingly, there was no difference between the likelihood of non-response between men and women at most ages, except for the oldest age group (80+) where women were 41% more likely to be non-responders than men (OR 1.41, 1.26–1.58). In the multivariate model the gradient of increasing odds of non-attendance with increasing deprivation was still present (test for trend $P < 0.001$) and this was most noticeable in the most deprived compared to the least deprived (OR 1.19, 95% CI 1.10–1.29).

Discussion

Of the 1000 patient questionnaire issued, 435 (43%) were returned. Since most of the people who responded had previously attended an eye screening appointment the responses need to be interpreted with some caution. Of the people who did respond to the patient questionnaire and of those who participated in the telephone interviews, a large proportion (over a quarter of respondents) did not recall talking to their GP or other primary care staff about DR screening. Many people did not fully understand the term 'diabetic retinopathy' and nearly 40% of respondents reported being offered a DR screen by their optometrist even though this service is not available in Derbyshire. In addition there were distinct preferences in the methods for making a screening appointment by patients in different age groups; older patients preferred fixed appointments whist younger patients preferred the flexibility of open appointments with access to electronic

Table 3 – Adjusted odds ratios for non-response to screening uptake.

Characteristic	Adjusted[a] odds ratios (95% confidence intervals)	
	Male	Female
Patient age		
80+	1.00	1.00
70–79	0.79 (0.71–0.89)	0.61 (0.55–0.67)
60–69	0.98 (0.88–1.09)	0.70 (0.63–0.77)
50–59	1.74 (1.57–1.95)	1.11 (1.00–1.24)
40–49	2.61 (2.31–2.95)	1.80 (1.59–2.04)
Under 40	3.13 (2.70–3.64)	2.23 (1.92–2.59)

	Type 2 diabetes	Type 1 diabetes	Type not stated
Patient age			
80+	1.00	1.00	1.00
70–79	0.67 (0.62–0.73)	0.40 (0.16–0.96)	0.73 (0.61–0.86)
60–69	0.80 (0.74–0.87)	0.80 (0.38–1.67)	0.85 (0.72–1.01)
50–59	1.42 (1.30–1.54)	1.44 (0.71–2.92)	1.22 (1.02–1.45)
40–49	2.20 (1.99–2.43)	1.99 (0.99–3.96)	2.04 (1.66–2.52)
Under 40	2.58 (2.21–3.01)	3.03 (1.54–5.98)	1.97 (1.58–2.45)
Deprivation			
(1) Least		1.00	
(2)		1.03 (0.95–1.11)	
(3)		0.97 (0.90–1.05)	
(4)		0.93 (0.86–1.00)	
(5) Most		1.19 (1.10–1.29)	
Not known		0.69 (0.59–0.80)	

a Each characteristic is mutually adjusted for the other characteristics in the table.

booking and reminder systems. People who did not attend screening appointments were generally positive about the process as ascertained during in-depth interviews, suggesting that non-attendance was often because they simply forgot to make an appointment or attend or were less inclined to attend if their previous screen result was clear. Some people also said that they had more important health issues to deal with.

Analysis of the routine screening data showed that younger people (and more so younger men and people with type 1 diabetes) and more deprived people were more likely not to make an appointment for DR screening when invited. In addition, a difference was not found in the likelihood of responding to screening invite between men and women except in the oldest age group where the proportion of women not responding to screening invite was higher than in men. This may be due to more women living alone and therefore being unable to get to a screening appointment although this information was not ascertained as part of this study. The authors were not able to look at the effect of distance from home to the screening venue but this is an important consideration and future studies should try to include this.

Comparison with other studies

The results are consistent with other studies that have shown that a recommendation from a GP or primary care physician to attend screening is an effective intervention.[19,20] This is significant since in this study it was found that nearly one third of patients did not recall discussing DR screening with their GP practice, that 11% of patients do not understand the term 'diabetic retinopathy' and 36% thought that they had been offered the DR screen by their optometrist even though this is not the case in Derbyshire. The findings suggest that there is a need to improve communication between patients and primary care practitioners generally.

When the authors discussed with patients why they had not attended their most recent screening appointment many said that they had other health issues to think about. This is consistent with observations from Leese and colleagues who pointed out that DR screening differs from other adult screening programmes because the target group already have significant contact with health services due to their underlying diabetes and other potential comorbidities.[16] This also highlights the need for caution when trying to generalise findings about screening uptake across screening programmes.

Using routinely-collected data an association was found between decreasing uptake and increasing deprivation which is consistent with the studies that have been published from the UK[21,22] and with studies of non-DR screening such as bowel cancer screening[23,24] and breast cancer screening.[25,26] Likewise, Leese et al.[22] showed that DR screening uptake is lower amongst younger people which is consistent with the findings of this study.

Strengths and limitations of the audit

This is a comprehensive audit of access to DR screening services in a large geographically and ethnically diverse population. It incorporates patient questionnaires and telephone interviews with multivariate analysis of routine data to determine correlates of non-attendance and barriers to screening uptake in a fixed-site, open invite model of screening delivery. The findings are of relevance to other population-based DR screening programmes that are delivered in a similar manner and may be useful for other types of screening programmes.

As noted above, the response rate from the postal questionnaire was 43%, however the characteristics of people who returned the questionnaire in terms of age, gender, type of diabetes and district of residence were broadly similar to those issued with it. Responses were lower from younger people and people from the inner city areas, reducing the generalisability of the findings.

Whilst Derby City has a high proportion of people from black and minority ethnic backgrounds, ethnicity is not collected routinely by the screening programme, limiting the analysis of ethnicity relating to screening uptake. There was an ecological correlation between lower uptake in the city where the proportion of BME residents is higher but this relationship could be confounded by deprivation which is also higher in the city. The postal questionnaires and telephone interviews were only conducted in English and further work is needed to understand any language or culture-specific barriers to screening that may exist.

Implications for screening programmes

The results have shown that efforts to increase uptake for DR screening should be focused on improving

communication between patients and the primary care team regarding screening uptake. Encouraging primary care practitioners, including pharmacists and optometrists to discuss DR screening with patients at every opportunity, including at annual reviews, may help clarify misunderstandings and increase the likelihood of screening uptake. In addition, interventions to increase uptake may be targeted towards more deprived communities and people who are diagnosed with diabetes at a young age (i.e. under 60), particularly those with type 1 diabetes. It is likely that many of these people are of working age and this study has shown that there are strong preferences for electronic methods of making appointments and being reminded about appointments in working-age people but that these are not necessarily shared with older people who make up the majority of the eligible population.

Next steps in Derbyshire

Following on from this work in Derbyshire, there has been a focus on the role that primary care can play in increasing uptake. Work is being targeted at the four practices with the highest rates of non-attenders. Together they are working to make the following changes: beginning to use 'diabetic eye disease' rather than 'retinopathy'; simplifying the screening invitation letters; contacting patients by post when they fail to attend rather than delay until the next health check; establishing a direct line between practices to the screening booking team to facilitate bookings for 'hard to engage' individuals when actually in the practice; working with the practices to minimise the exclusion of patients from screening; reconciling practice and screening patient listings to standardise names, addresses, screening status; developing online patient access booking and text reminder service to increase accessibility to male and younger cohorts; maintaining the availability of out of hours screening provision and agreement to provide ad hoc sessions as necessary for working-age patients and delivering best practice workshops for GP administrative and clinical staff.

Author statements

Ethical approval

The Derby City ethics committee deemed this work to be service evaluation and did not therefore require ethics approval. The confidentiality of patients' responses was assured and patients were given the option to opt out if they did not wish to be contacted by telephone when they were posted the questionnaire.

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None.

Competing interests

None declared.

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